

CHAPTER 191.

**STATE PLAN FOR THE CHILDREN WITH SPECIAL HEALTH CARE NEEDS
PROGRAM**

12VAC5-191-10. Definitions.

The following words and terms, when used in this regulation, shall have the following meaning, unless the context clearly indicates otherwise:

"Appeal" means the client's right to seek relief from an unfavorable decision in obtaining services or assistance included in the plan.

"Applicant" means an individual who applies for the services under this regulation. An application may be filed for or on behalf of a minor or person under a legal disability by a parent, legal guardian, and attorney in fact, or an attorney at law.

"Bleeding disorders" means inherited problems in coagulation caused by missing or poorly functioning proteins in the blood such as hemophilia and von Willebrand Disease.

"Board" means the State Board of Health.

"Care coordination" means a process that links individuals and their families to services and resources in a coordinated effort to maximize their potential and provide them with optimal health care.

"Center" means a unit providing Care Connection for Children services.

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“CCC” means Care Connection for Children.

“Children and youth with special health care needs” means individuals who are ages birth to their twenty-first birthday and have, or are at increased risk for, a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

“Client” means an individual who meets all the eligibility criteria for a program, and has been accepted for services.

"Commissioner" means the Commissioner of Health.

“Community-based” means a framework within which a variety of programs work together to meet the many, varied needs of children, youth, and families in communities.

“CSHCN” mean children with special health care needs.

“Culturally-competent” means the ability to provide services to clients that honor different cultural beliefs, interpersonal styles, attitudes and behaviors and the use of multicultural staff in the policy development, administration, and provision of those services.

"Department" means the state Department of Health and includes the central office, regional offices, health districts, and local health departments.

"Developmental disorder" means a delay(s) in maturation or deviant maturation of physical, language, sensory, motor, cognitive, social, learning or self-help capabilities to the extent that

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there is a negative impact on a child's ability to adapt to or cope with the typical environmental demands as expected for chronological age.

“Direct health care services” means medically necessary services for the treatment and monitoring of a condition (s) covered by the program. The services are generally delivered one-on-one between a health care professional and a client in an office, home, clinic, outpatient department, or hospital.

"Director" means the Director, Children with Special Health Care Needs Program.

"Division" means the Division of Child and Adolescent Health.

“Enabling services” means support services that allow or provide for access to and the receipt of benefits from an array of basic health care services.

“Family” means the client and other such household members who together constitute one economic unit. An economic unit is one or more individuals who generally reside together and share income.

“Family-centered care” means an approach to the planning, delivery, and evaluation of health care whose cornerstone is active participation between families and professionals. Family-centered care recognizes that families are the ultimate decision makers for their children, with children gradually taking on more and more of this decision-making themselves.

“Family-to-family support” means the provision of information and peer support among families having experience with family members having special health care needs.

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“Guardian” means a court-appointed guardian of the person.

“Information and referral services” means assisting clients and their families to find available services, responding to inquiries from the general public, and disseminating information for accessing specific services.

“MCH” means maternal and child health.

“Medical home” means a concept in which the child has an ongoing source of health care from a primary care physician who works together with the family to ensure that the child has accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective medical care.

“Parent” means a biological, adoptive or stepparent.

"Plan" means the State Plan for the Children with Special Health Care Needs Program prepared pursuant to Title V of the United States Social Security Act, as amended.

“Pool of Funds” means funds designated for payment of direct health care services. Access to the pool is not an entitlement and is subject to availability of funds and guidelines that govern its eligibility and coverage of services.

“Population-based services” means preventive interventions and personal health services developed and available for the entire MCH population of the Commonwealth rather than for individuals in a one-on-one situation.

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"Program" means the Children with Special Health Care Needs Program.

"Provider" means an individual or agency that provides a service under an agreement between the individual or agency and the Children with Special Health Care Needs Program or its contractors.

"Resident" means an individual who resides within the geographical boundaries of the Commonwealth.

"Services" means those activities provided or arranged by the various programs within the Children with Special Health Care Needs Program.

"Sickle cell disease" means any inherited hemoglobin pattern with a predominance of hemoglobin (S) in absence of, or greater than normal hemoglobin (A); or hemoglobin S with another hemoglobin variant such as C, D, or E or beta thalassemia.

"Sickle Cell Program Manager" means an employee of the Pediatric Comprehensive Sickle Cell Clinic Network who is designated to be responsible for the administration of the statewide Pediatric Comprehensive Sickle Cell Clinic Network.

"Transition services" means assisting the client and his family in the process of making necessary changes from life as a youth with special health care needs to life as an adult with special health care needs. Aspects to be addressed include health and wellness; education, vocation, and employment; mobility, transportation, and recreation; and legal, insurance, disability benefits, and housing.

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“Underinsured” means having medically necessary service needs that exceed an individual’s health insurance coverage limits.

“Uninsured” means having no private health insurance or state or federal medical assistance coverage.

12VAC5-191-20. Guidance documents.

The commissioner may issue guidance documents that interpret these regulations and provide guidance for their implementation. Such documents shall be reviewed and revised whenever these regulations are reviewed, and may also be amended or revised as needed to meet changing circumstances.

12VAC5-191-30. Delegation of authority.

The commissioner hereby delegates the authority to supervise the day-to-day activities required to administer the plan to the Director, Children with Special Health Care Needs Program. The director shall be responsible for the efficient and effective implementation of the plan and shall be accountable to the commissioner or his designee.

12VAC5-191-40. Scope and content of the Children with Special Health Care Needs Program.A. Mission.

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The Children with Special Health Care Needs Program promotes the optimal health and development of individuals living in the Commonwealth with special health care needs by working in partnership with families, service providers, and communities.

B. Scope.

The scope of the Children with Special Health Care Needs Program includes the following:

1. Direct health care services.
2. Enabling services.
3. Population-based services.
4. Assessment of community health status and available resources.
5. Policy development to support and encourage better health.

The Children with Special Health Care Needs Program administers the following networks and services:

1. Care Connection for Children.
2. Child Development Services.
3. Virginia Bleeding Disorders Program.
4. Pediatric Screening and Genetics Services.
 - a. Virginia Newborn Screening System.

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- b. Virginia Congenital Anomalies Reporting and Education System.
 - 5. Virginia Sickle Cell Awareness Program.
 - 6. Pediatric Comprehensive Sickle Cell Clinic Network.
- C. Target population.

The target population to receive services from the networks and programs within the Children with Special Health Care Needs Program are the following:

- 1. Residents of the Commonwealth.
- 2. Individuals between the ages of birth and their twenty-first birthday except that the Virginia Bleeding Disorders Program and the Virginia Sickle Cell Awareness Program serve individuals of all ages.
- 3. Individuals diagnosed as having, or are at increased risk for having, a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

Each network and program within the CSHCN Program has its own specific eligibility criteria.

- D. Goals.

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The Title V national performance measures, as required by the federal Government Performance and Results Act (GPRA-Pub. L. 103-62), are used to establish the program goals.

12VAC5-191-50. Availability of funds; no entitlement.

Receipt of federal funds and subsequent administration of the State Plan for the Children with Special Health Care Needs are contingent upon annual federal review, approval, and compliance with other applicable federal law and regulations as outlined in USC §§701-710, Subchapter V, Chapter 7, Title 42 and CFR, Secretary of Health and Human Services, Chapter I, Title 42, and Subtitle A, Title 45.

Expenditures shall be limited to available funding. These regulations do not create any legally enforceable right or entitlement to payment for medical services on the part of any person or any right or entitlement to participation.

For those program services and assistance requiring financial eligibility, the funds shall be committed on behalf of the eligible client based on the date that the programs, within the CSHCN Program, receive the original signed financial eligibility application.

12VAC5-191-60. Emergency suspension of services.

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The commissioner may suspend any portion of the plan, including services provided, to ensure the financial integrity of the Children with Special Health Care Needs Program. The commissioner shall report any action taken under the provisions of this section to the Board of Health at its next scheduled meeting.

12VAC5-191-70. Financial requirements.

For those program services and assistance requiring financial eligibility, the determination shall be conducted in accordance with the State Board of Health Regulations Governing Eligibility Standards and Charges for Health Care Services to Individuals, 12 VAC 5-200 and its guidance documents that are currently in effect.

Applicants who are eligible for financial assistance under this plan must demonstrate that they are not eligible for other available state and federal medical assistance programs. An application for such state or federal assistance programs must be completed and a denial of eligibility received in order to qualify for financial assistance under this plan. The Children with Special Health Care Needs Program may limit financial assistance until the appropriate applications for the medical assistance programs have been processed for acceptance or denial.

12VAC5-191-80. Appeal process.

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- A. An applicant for or client in receipt of services or assistance, as defined in this plan, may appeal the following actions:
1. Denial of services or assistance.
 2. Termination of services or assistance.
 3. Adverse determination regarding financial eligibility.

There are no further rights of appeal except as set forth in this part. Applicants or clients have no right of appeal of a denial of services or assistance because of a lack of funds.

- B. The applicant or client has the right to receive a written statement of the reasons for denial and be informed in writing of the appeal process, including time limits.
- C. If a client already receiving services or assistance is denied those services or assistance, a written notice of termination including the reason of denial shall be given 30 days in advance of discontinuing services.
- D. First level of appeal: An individual or his representative may make a written or oral appeal to the employee designated to be responsible for the administration of the different programs (the Care Connection for Children Program Director, Administrative Director for the Child Development Services, Bleeding Disorders Program Coordinator, or Sickle Cell Program Manager) within 30 days of the denial

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of service. The respective program director, administrative director, program coordinator, or program manager shall review and make a written decision to the individual or his representative within 15 days from the date of receipt of the appeal.

E. Second level of appeal: If the individual is not satisfied with the decision provided at the first level of appeal, the individual may appeal the decision in writing to the Director of the Children with Special Health Care Needs Program within 30 days of the denial from the individual program.

F. Upon receipt of the appeal, the director shall review and make written recommendations to the commissioner, or the commissioner's designee, within 15 days. The director shall consider all written information and may confer, as deemed necessary, with the department's adjudication officer in the Office of Family Health Services or other relevant experts.

G. Within 45 days following the date on which an appeal is filed, the commissioner, or commissioner's designee, shall make a final decision.

12VAC5-191-90. Privacy.

A. The Children with Special Health Care Needs Program and program subcontractors shall protect the privacy of the client's personal health information and the confidentiality of medical records in accordance with §§ 2.2-3700 through 2.2-3705.1,

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2.2-3705.5, 2.2-3800 through 2.2-3809, 32.1-40, 32.1-41, 32.1-64.2, 32.1-67.1, 32.1-69, 32.1-69.2, 32.1-127.1:03, and 32.1-127.1:04 of the Code of Virginia; the federal Health Insurance Portability and Accountability Act of 1996 (42 USC §§ 1320 d et seq. and 45 CFR Part 164); and Title V of the Social Security Act (42 USC §§701-710, Subchapter V, Chapter 7 and 42 CFR 51a.6).

- B. Access to minor's health records and the authority to consent to surgical and medical treatment for certain minors shall be administered in accordance §§ 20-124.6 and 54.1-2969 of the Code of Virginia, respectively.

- C. Surveillance and investigation shall be consistent with §§ 32.1-40, 32.1-41, 32.1-66 and 32.1-39 of the Code of Virginia.

- D. The department's children with special health care needs program and its contractors shall maintain security and confidentiality of databases in accordance with applicable federal and state laws and regulations.

12VAC5-191-100. Contracts with providers.

- A. The program may choose to administer a pool of funds for payment of direct health care services for the uninsured and underinsured clients subject to availability of funds and guidelines that govern its eligibility and coverage of services.

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- B.** The program and its contractors are payors of last resort for direct health care services. All other payment sources, including Title XVIII (Medicare), Title XIX (Medicaid and its EPSDT Program), Title XXI (SCHIP), military health insurance, private health insurance, any other state and federal medical assistance program, or any entity that contracts to pay medical care costs for persons eligible for medical assistance in the Commonwealth, shall be exhausted prior to program payment.
- C.** The program and its contractors will not pay any portion of the bill that is not covered by any insurer, state and federal medical assistance program, or any entity that contracts to pay medical care costs for persons eligible for medical assistance in the Commonwealth unless the service is totally nonreimbursable by them.
- D.** Providers of direct health care services are limited to those providers who:
1. Have credentials, licensure or certification in the clinical specialty to provide the approved services.
 2. Accept the Medicaid fee-for-service rate of reimbursement for the specific service based upon the appropriate code set to identify procedures, services, and diagnoses as approved for use by the federal Centers for Medicare and Medicaid Services.
 3. Accept the amounts as negotiated by the program, or a contractor on its behalf, as payment in full on behalf of the program, client, and his family or legal guardian.
- E.** Paraprofessional staff and volunteers may provide services under the direction of a provider who has credentials, licensure, or certification.

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12VAC5-191-110. Special projects.

- A. When approved by the commissioner or his designee, the plan does not preclude establishment of "Demonstration Projects" to test alternate means of service delivery. All such projects shall be relevant to the services for children with special health care needs as provided through the administration of the plan.
- B. The plan does not preclude seeking funding from other available funding sources to perform a special project.

12VAC5-191-120. Federally required assurances and certifications.

- A. The Children with Special Health Care Needs Program is funded by the Title V of the federal Social Security Act, Maternal and Child Health Services Block Grant which is matched by state funds. The department is required to comply with the following:
1. Civil Rights Assurance (45 CFR Part 80).
 2. Assurance concerning the Handicapped (45 CFR Part 84).
 3. Assurance concerning Sex Discrimination (45 CFR Part 86).
 4. Assurance concerning Age Discrimination (45 CFR Part 90 and 45 CFR Part 91).
 5. Human Subjects Certification, when applicable (45 CFR Part 46).
 6. Certifications regarding Drug-free Workplace, Debarment and Suspension, Lobbying, Program Fraud Civil Remedies, and Environmental Tobacco Smoke.
 7. Regulatory Provisions for Block Grants (45 CFR 96.50 (e)).

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- B. For funding received from other federal sources, the department is required to comply with the Office of Management and Budget Circular A-87, “Cost Principles for State, Local, and Indian Tribal Governments” as published in 67 FR 52558.

12VAC5-191-130. Federal stipulations for use and non-use of funds.

- A. The MCH Services Block Grant has, as its general purpose, the improvement of the health of all mothers and children in the nation consistent with the applicable health status goals and national health objectives established by the Secretary of Health and Human Services. The funds enable each state to:
1. Provide and assure mothers and children (in particular those with low income or with limited availability of health services) access to quality maternal and child health services;
 2. Reduce infant mortality and the incidence of preventable diseases and handicapping conditions among children;
 3. Provide rehabilitative services for blind and disabled individuals under the age of 16 years receiving benefits under Title XVI (Supplemental Security Income), to the extent medical assistance for such services is not provided under Title XIX (Medicaid); and

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4. Provide and promote family-centered, community-based, coordinated care for children with special health care needs and to facilitate the development of community-based systems of service for such children and their families.
- B. Federal requirements prohibit MCH Services Block Grant funds from being used for the following purposes:
1. Purchase of major medical equipment.
 2. Cash payments to intended recipients of health services.
 3. Purchase or improvement of land; the purchase, construction or permanent improvement of any building or other facility (other than minor remodeling).
 4. Providing funds for research or training to any entity other than a public or nonprofit private entity.
 5. Satisfying any requirement for the expenditure of non-federal funds as a condition for the receipt of federal funds. Further, federal funds from other block grants (e.g., Preventive Health) may be transferred into the MCH Services Block Grant Program by states, but MCH Block Grant funds may not be transferred to any other program.
- C. For funding received from other federal sources, the department is required to comply with the Office of Management and Budget Circular A-87, "Cost Principles for State, Local, and Indian Tribal Governments" as published in 67 FR 52558.

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12VAC5-191-140. Parent, legal guardian and client rights and responsibilities.

The parent, legal guardian, or client rights and responsibilities shall be described in existing program policies and shall be given to the client upon acceptance to the program.

12VAC5-191-150. Closure of client to the program.

- A. The reasons for closure of a client to the program shall be in accordance with existing department eligibility guidance documents as stated in 12 VAC5-191-70.
- B. If, at the time of closure to the program, the client still needs medical care for the condition for which he was in the program and for the service that he has been receiving from the program, the client will be referred to another source. The services may terminate only following notice to the client that such services will be terminated. Medical care services cannot be terminated for clients receiving ongoing care without making a good faith effort to secure alternative care.

12VAC5-191-160. Transfer of client.

Transfer of a client geographically among the program's centers or clinics shall be in accordance with existing program policies.

12VAC5-191-170. Description of the Care Connection for Children network.

Care Connection for Children is a statewide network of Centers of Excellence for Children with Special Health Care Needs that facilitates access to comprehensive medical and support

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services, that are collaborative, family-centered, culturally-competent, fiscally responsible, community-based, coordinated and outcome-oriented to children and youth with special health care needs and their families.

12VAC5-191-180. Scope and content of the Care Connection for Children network.A. Mission.

The Care Connection for Children network promotes the optimal health and development of children and youth living in the Commonwealth with special health care needs by working in partnership with families, service providers, and communities.

B. Scope of services.

The Care Connection for Children network provides the following enabling services:

1. Assistance in accessing specialty medical services and a medical home.
2. Care coordination.
3. Medical insurance benefits evaluation and coordination that may include services that promote the access to and the understanding of the use of private health insurance and state and federal medical assistance programs.
4. Information and referral.

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5. Collaboration with the Virginia Department of Education and its Education in Hospitals Program to provide consultation for families, educators and school administrators.
6. Transition from child to adult oriented health care system.
7. Family-to-family support.
8. Training and technical assistance for community providers.
9. Promote a family-centered, community-based, and culturally competent service delivery system through advisory councils.

Based on community need, the Care Connection for Children network may provide direct health care services.

C. Criteria to receive services from Care Connection for Children.

Children and youth are eligible to receive services from Care Connection for Children if they are:

1. Residents of the Commonwealth.
2. Between the ages of birth and their twenty-first birthday.
3. Diagnosed with a disorder that:
 - a. Has a physical basis;
 - b. Has lasted, or is expected to last, at least 12 months; and

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- c. Produces one of more of the following sequelae:
- (1) Need for health care and ancillary services over and above the usual for the child's age, or for special ongoing treatments, interventions, or accommodation at home or school;
 - (2) Limitation in function, activities, or social role in comparison with healthy age peers in the general areas of physical, cognitive, emotional, and social growth and development;
 - (3) Dependency on one of the following to compensate for, or minimize limitation of, function, activities, or social role: medications, special diet, medical technology, assistive devices or personal assistance.

No financial eligibility criteria are required for clients to receive the enabling services.

However clients, who meet the above criteria, must also meet the financial requirements for eligibility for access to a pool of funds for payment of their direct health care services.

D. Goals.

The Title V national performance measures, as required by the federal Government Performance and Results Act (GPRA-Pub. L. 103-62), are used to establish the program goals. The following goals shall change as needed to be consistent with the Title V national performance measures:

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1. Families of children with special health care needs will partner in decision making at all levels and will be satisfied with the services they receive.
2. All children with special health care needs will receive coordinated, ongoing, comprehensive care within a medical home.
3. All families of children with special health care needs will have adequate private or public insurance or both to pay for the services they need.
4. All children will be screened early and continuously for special health care needs.
5. Community-based service systems will be organized so families can use them easily.
6. All youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

12VAC5-191-190. Care Connection for Children Pool of Funds.

Based on availability of funds, the Children with Special Health Care Needs Program may choose to administer a Care Connection for Children pool of funds for payment of direct medical care services for the uninsured and underinsured clients. The commissioner or his designee may issue a guidance document that interprets these regulations and provides guidance for their implementation. The guidance document for the Pool of Funds shall include the financial requirements for eligibility as stated in 12 VAC5-191-70, the policies for authorization of services, and the contractual assurances as noted in this regulation. The

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guidance document will assure that the funds are allocated to the children with the greatest financial need after all health insurance, federal, state, and community financial resources have been exhausted. At a minimum, the guidance document shall be reviewed at least annually and revised as needed, whenever the regulations are reviewed, and also may be amended or revised as needed to meet changing circumstances.

12VAC5-191-200. Description of the Child Development Services network.

The Child Development Services is a statewide network of Child Development Clinics that facilitates the availability and accessibility of comprehensive, interdisciplinary developmental services for children and youth suspected to have or diagnosed with developmental, learning, or behavioral disorders.

12VAC5-191-210. Score and content of the Child Development Services Program.A. Mission.

The Child Development Services Program promotes the optimal physical, language, cognitive, social, learning, self-help, behavioral, and emotional development and well-being of children.

B. Scope of services.

The Child Development Clinics provide pediatric services in the specialty area of developmental and behavioral pediatrics. This health care field specializes in the

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diagnosis and treatment of developmental and psychosocial aspects of pediatric health care including developmental disorders and emotional, behavioral, and psychosomatic problems.

Services offered at each clinic location may vary according to the needs of the community, expertise of the professional staff, and the overall goals and objectives for the current program.

The Child Development Services network provides the following direct health care services and enabling services:

1. Interdisciplinary evaluations that may include a pediatric medical examination, nurse evaluation, psychosocial history, psychological assessment, and educational evaluation.
2. Treatment planning that may include the evaluation team developing a written report that integrates their findings, establishes diagnoses, and formulates recommendations for each client.
3. Care coordination.
4. Consultation.
5. Screenings for early identification of persons with developmental disorders.
6. Screening services to assist other agencies in their program implementation as may be described in a contract or memorandum of agreement.

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7. Information and referral.
8. Intervention services that may include medical, psychosocial, educational, or interdisciplinary treatment services.
9. Training and technical assistance for community providers.

C. Criteria to receive services from Child Development Services.

Children and youth are eligible to receive services from Child Development Services if they are:

1. Residents of the Commonwealth.
2. Between the ages of birth and their twenty-first birthday.
3. Suspected to have or diagnosed with developmental, emotional or behavioral disorder or presence of severe or multiple risk factors for these conditions.

No financial eligibility criteria are required for clients to receive the enabling services.

However clients, who meet the above criteria, must also meet the financial requirements to receive direct health care services based on a sliding scale charge schedule. The amount of the required charge shall be in accordance with the State Board of Health Regulation Governing Eligibility Standards and Charges for Health Care Services to Individuals, 12VAC5-200.

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D. Goals.

The Title V national performance measures, as required by the federal Government Performance and Results Act (GPRA-Pub. L. 103-62), are used to establish the program goals. The following goals shall change as needed to be consistent with the Title V national performance measures:

1. Children who are at greatest risk for developmental, emotional and behavioral disorders and in need of related services will receive early screening, diagnosis, and assistance in finding and accessing needed services.
2. Other state and local agencies will receive assistance in providing effective coordinated services for persons with special health care needs.

12VAC5-191-220. Description of the Virginia Bleeding Disorders Program.

The Virginia Bleeding Disorders Program supports a statewide network of comprehensive care centers to promote coordinated, family-centered, culturally-competent, multidisciplinary system of care for clients of all ages with inherited bleeding disorders and their families.

12VAC5-191-230. Scope and Content of the Virginia Bleeding Disorders Program.A. Mission.

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Virginia Bleeding Disorders Program improves the availability and accessibility of comprehensive care for clients with inherited bleeding disorders and their families.

B. Scope of services.

In collaboration with a network of comprehensive bleeding disorders clinics in the Commonwealth, services are provided by a multidisciplinary team that focuses on the physical, emotional, social, educational, financial and workplace impact of inherited bleeding disorders. The comprehensive care team collaborates closely with the client's primary care provider within their community.

The Virginia Bleeding Disorders Program provides the following enabling services:

1. Assistance in accessing comprehensive specialty health care services for clients with inherited bleeding disorders and a medical home.
2. Care coordination.
3. Insurance case management that may include a comprehensive resource assessment, consultation, and referral of eligible individuals to third party payers; education and assistance to individuals regarding health care choices relevant to insurance options; procurement of grants for the funding of third party medical coverage; and assistance to eligible individuals in the health insurance application

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and enrollment process and procurement of the least costly and beneficial medical coverage.

4. Information and referral.
5. Collaboration with the Virginia Department of Education and its Education in Hospitals Program to provide consultation for families, educators, and school administrators.
6. Transition from child to adult oriented health care system.
7. Family-to-family support.
8. Training and technical assistance for community providers.
9. Promotion of quality assurance and policy development through the Hemophilia Advisory Board.

C. Criteria to receive services of Virginia Bleeding Disorders Program.

Individuals are eligible to receive services from the Virginia Bleeding Disorder Program if they are:

1. Residents of the Commonwealth.
2. Any age.
3. Diagnosed as having an inherited bleeding disorder.
4. Clients of a comprehensive bleeding disorder clinic.

No financial eligibility criteria are required for clients to receive the enabling services.

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However clients, who meet the above criteria, must also meet the financial requirements for eligibility for access to a pool of funds for payment of their direct health care services.

D. Goals.

The Title V national performance measures, as required by the federal Government Performance and Results Act (GPRA-Pub. L. 103-62), are used to establish the program goals. The following goals shall change as needed to be consistent with the Title V national performance measures:

1. Clients with inherited bleeding disorders will partner in decision making at all levels and will be satisfied with the services they receive.
2. Clients with inherited bleeding disorders will receive coordinated, ongoing, comprehensive specialized care in partnership with their community-based primary care provider.
3. Clients with inherited bleeding disorders will have adequate private or public insurance or both to pay for the services they need.
4. All youth with inherited bleeding disorders will participate in preparing for transition to adult life, including adult health care, work and independence.

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12VAC5-191-240. Bleeding Disorders Pool of Funds.

Based on availability of funds, the Children with Special Health Care Needs Program may choose to administer a Bleeding Disorders Pool of Funds for payment of direct medical care services for the uninsured and underinsured clients. The commissioner or his designee may issue a guidance document that interprets these regulations and provides guidance for their implementation. The guidance document for the pool of funds shall include the financial requirements for eligibility as stated in 12 VAC5-191-70, the policies for authorization of services, and the contractual assurances as noted in this regulation. The guidance document will assure that the funds are allocated to the children with the greatest financial need after all health insurance, federal, state, and community financial resources have been exhausted. At a minimum, the guidance document shall be reviewed at least annually and revised as needed, whenever the regulations are reviewed, and also may be amended or revised as needed to meet changing circumstances.

12VAC5-191-250. Pediatric Screening and Genetics Services.

The Pediatric Screening and Genetics Services unit works to improve the health of children and families by preventing birth defects and developmental disabilities, promoting optimal child development, and promoting health and wellness among children and adolescents living with disabilities.

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Pediatric Screening and Genetics Services include several programs, services, and projects, two of which are the Virginia Newborn Screening System and the Virginia Congenital Anomalies Reporting and Education System.

12VAC5-191-260. Scope and content of the Virginia Newborn Screening System.

The Virginia Newborn Screening System consists of two components: (1) Virginia Newborn Screening Services and (2) Virginia Early Hearing Detection and Intervention Program.

A. Virginia Newborn Screening Services.1. Mission.

The Virginia Newborn Screening Services prevents mental retardation, permanent disability, or death through early identification and treatment of infants who are affected by selected inherited disorders.

2. Scope of services.

The Virginia Newborn Screening Services provides a coordinated and comprehensive system of services to assure that all infants receive a screening test after birth for selected inherited metabolic, endocrine, and hematological disorders

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as defined in Regulations Governing Virginia Newborn Screening Services, 12 VAC 5-71.

These population-based, direct, and enabling services are provided through:

- a. Biochemical dried bloodspot screening tests.
- b. Follow up of abnormal results.
- c. Diagnosis.
- d. Education to health professionals and families.
- e. Expert consultation on abnormal results, diagnostic testing, and medical and dietary management for health professionals.

Medical and dietary management is provided for the diagnosed cases and includes assistance in accessing specialty medical services and referral to Care Connection for Children.

The screening and management for specified diseases are governed by Regulations Governing Virginia Newborn Screening Services, 12 VAC 5 71.

3. Criteria to receive Virginia Newborn Screening Services.

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All infants born in the Commonwealth are eligible for the screening test for selected inherited disorders.

4. Goal.

The Title V national performance measures, as required by the federal Government Performance and Results Act (GPRA-Pub. L. 103-62), are used to establish the program goals. The following goal shall change as needed to be consistent with the Title V national performance measures:

All infants will receive appropriate newborn bloodspot screening, follow up testing, and referral to services.

B. Virginia Early Hearing Detection and Intervention Program.

1. Mission.

The Virginia Early Hearing Detection and Intervention Program promotes early detection of and intervention for infants with congenital hearing loss to maximize linguistic and communicative competence and literacy development.

2. Scope of services.

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The Virginia Early Hearing Detection and Intervention Program provides services to assure that all infants receive a hearing screening after birth, that infants needing further testing are referred to appropriate facilities, that families have the information that they need to make decisions for their children, and that infants and young children diagnosed with a hearing loss receive appropriate and timely intervention services. These population-based and enabling services are provided through:

- a. Technical assistance and education to new parents.
- b. Collaboration with physicians and primary care providers.
- c. Technical assistance and education to birthing facilities and those persons performing home births.
- d. Collaboration with audiologists.
- e. Education to health professionals and general public.

Once diagnosed, the infants are referred to early intervention services. The screening and management for hearing loss are governed by the regulation, Virginia Hearing Impairment Identification and Monitoring System, 12 VAC 5-80.

3. Criteria to receive services from the Virginia Early Hearing Detection and Intervention Program.

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- a. All infants born in the Commonwealth are eligible for the hearing screening.
- b. All infants who are residents of the Commonwealth and their families are eligible for the Virginia Early Hearing Detection and Intervention Program.

4. Goals.

The Title V national performance measures, as required by the federal Government Performance and Results Act (GPRA-Pub. L. 103-62), are used to establish the program goals. The following goals shall change as needed to be consistent with the Title V national performance measures:

All infants will receive screening for hearing loss no later than one month of age, achieve identification of congenital hearing loss by three months of age, and enroll in appropriate intervention by six months of age.

12VAC5-191-270. Description of the Virginia Congenital Anomalies Reporting and Education System.

The Virginia Congenital Anomalies Reporting and Education System (VaCARES) is a birth registry of children under two years of age diagnosed with congenital anomalies using data from documents such as birth certificates filed with the State Registrar of Vital Records,

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hospital medical records, and newborn screening system records. It is both a reporting and an education system.

12VAC5-191-280. Scope and content of the Virginia Congenital Anomalies Reporting and Education System.

A. Mission.

The Virginia Congenital Anomalies Reporting and Education System promotes the evaluation of the possible causes of birth defects, the improvement in the diagnosis and treatment of children with birth defects, and the provision of information to parents and health professionals about the health resources available to aid such children.

B. Scope of services.

The Virginia Congenital Anomalies Reporting and Education System provides the following population-based and enabling services:

1. Identification of children having certain birth defects using data from documents such as birth certificates filed with the State Registrar of Vital Records, hospital medical records, and newborn screening system records.

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2. Collection of data to evaluate the possible causes of birth defects.
3. Publication of birth defect surveillance data.
4. Technical assistance and education to health professionals and parents.
5. Referral to Care Connection for Children.

This system is governed by § 32.1-69.1 of the Code of Virginia.

C. Criteria to receive services from VaCARES.

Children with selected birth defects who are under 2 years of age and residents of Virginia are eligible for the services.

D. Goals.

1. Children with birth defects will receive early diagnosis and assistance in finding and accessing health care services.
2. Birth defect surveillance data will be used in making decisions regarding health services planning and to promote scientific collaboration for the prevention of birth defects.

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12VAC5-191-290. Description of the Virginia Sickle Cell Awareness Program.

The Virginia Sickle Cell Awareness Program (VASCAP) is a statewide program for the education and screening of individuals for the disease of sickle cell anemia or sickle cell trait and for such other genetically related hemoglobinopathies.

12VAC5-191-300. Scope and Content of the Virginia Sickle Cell Awareness Program.**A. Mission.**

The Virginia Sickle Cell Awareness Program promotes awareness and provides access to screening and follow-up education for individuals and families identified with sickle cell disease and other genetically related hemoglobinopathies.

B. Scope of services.

The Virginia Sickle Cell Awareness Program provides the following enabling services in collaboration with local health departments:

1. Assistance for those unable to pay in accessing screening that includes screening for the purposes of preconceptual counseling, prenatal diagnosis, and the identification of sickle cell disease and related hemoglobinopathies in the child and adult.
2. Individual, community, and professional consultation about sickle cell disease and related hemoglobinopathies.

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3. Post-screening counseling regarding carrier status or treatment.
4. Training and technical assistance for community providers.
5. Collaboration with Virginia Newborn Screening Program to track infants identified with sickle cell disease and related hemoglobinopathies to insure early parent education about the specific hemoglobinopathy, encourage confirmatory testing, and provide information about a network of Pediatric Comprehensive Sickle Cell Clinics located throughout the state.

C. Criteria to receive services from the Virginia Sickle Cell Awareness Program.

Individuals are eligible to receive services from the Virginia Sickle Cell Awareness Program if they are:

1. Residents of the Commonwealth.
2. Any age.

No financial eligibility criteria are required for clients to receive enabling services.

However, clients being screened for hemoglobin variants through local health departments, who meet the above criteria, must also meet the financial requirements based on a sliding scale charge schedule. The amount of the required charge shall be in accordance with the State Board of Health Regulation Governing Eligibility Standards and Charges for Health Care Services to Individuals, 12 VAC 5-200.

D. Goal.

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Individuals with the disease of sickle cell anemia or sickle cell trait and other genetically related hemoglobinopathies will receive early diagnosis and assistance in finding and accessing health care services.

12VAC5-191-310. Description of the Pediatric Comprehensive Sickle Cell Clinic**Network.**

The Pediatric Comprehensive Sickle Cell Clinic Network is a statewide group of clinics, located in major medical centers, that provide comprehensive medical and support services that are collaborative, family-centered, culturally-competent, community-based and outcome-oriented for newborns identified from newborn screening, children, and youth living with sickle cell disease.

12VAC5-191-320. Scope and content of the Pediatric Comprehensive Sickle Cell Clinic**Network.****A. Mission.**

The Pediatric Comprehensive Sickle Cell Clinic Network promotes the optimal health and development of children and youth living in the Commonwealth with sickle cell disease by working in partnership with families, service providers, community-based sickle cell programs and the Virginia Sickle Cell Awareness Program.

B. Scope of services.

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The Pediatric Comprehensive Sickle Cell Clinic Network provides the following direct health care services and enabling services:

1. Multidisciplinary evaluation and treatment from a team of professionals that may include physician, nurse, social worker, and educational consultant.
2. Assistance in tracking newborns identified with sickle cell disease to insure confirmation of newborn screening results and early access to care.
3. Assistance in accessing comprehensive care and a medical home.
4. Educational genetic counseling and diagnostic family studies to insure the accurate diagnosis of sickle cell disease.
5. Parent and client education across the life span.
6. Collaboration with primary care providers.
7. Information and referral to community-based sickle cell support programs.
8. Collaboration with the Virginia Department of Education and its Education in Hospitals Program to provide consultation for families, educators and school administrators.
9. Transition from child to adult oriented health care system.
10. Family-to-family support.
11. Training and technical assistance for community providers.

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12. Collection of surveillance data to insure clients are receiving services consistent with their level of risk.

C. Criteria to receive services from the Pediatric Comprehensive Sickle Cell Clinic Network.

Children and youth are eligible to receive services from the Pediatric Comprehensive Sickle Cell Clinic Network if they are:

1. Residents of the Commonwealth.
2. Between the ages of birth and their twenty-first birthday.
3. Diagnosed with sickle cell disease.

No financial eligibility criteria are required for clients to receive the enabling services.

However, clients receiving direct health care services, who meet the above criteria, must also meet the financial requirements based on a sliding scale charge schedule of the major medical center.

D. Goals.

The Title V national performance measures, as required by the federal Government Performance and Results Act (GPRA-Pub. L. 103-62), are used to establish the program goals. The following goals shall change as needed to be consistent with the Title V national performance measures:

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1. Families of children with sickle cell anemia will partner in decision making at all levels and will be satisfied with the services they receive.
2. All children with sickle cell anemia will receive coordinated, ongoing, comprehensive care within a medical home.
3. All families of children with sickle cell anemia will have adequate private or public insurance or both to pay for the services they need.
4. Community-based service systems will be organized so families can use them easily.
5. All youth with sickle cell anemia will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.